

Perceptions of Marital Identity of a Spouse Living Separate from their Spouse with Dementia

Thesis

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Abstract

Couples who want to stay together until their end years often have to keep their bond strong and be prepared to face life's hardships with each other. Sometimes illness can affect one of the partners, which can cause stress on the relationship. Couples who have one spouse with dementia may face many difficulties within their marriage. Some spouses may not be able to care for their ill spouse adequately and have to place their spouse in residential care. The separation of the spouse can produce many changes within the marriage. There is little research on the bond and identity that spouses have on their marriage once their spouse with dementia is placed in residential care. The study focused on the perceptions of the marriage by the independent spouse. The purpose of the study was to determine if and how the spousal identity of the couple has been affected by having to institutionalize the spouse with dementia. The study examined how the connectedness that the independent spouse feels towards the institutionalized spouse has been altered since the separation. The study had nine interviews with various spouses who live apart from their spouse who has dementia. After the interviews were conducted the data was analyzed to discover reoccurring themes within each of the interviews. Results found that spouses have accepted their current roles in the marriage as not being the primary caregiver, but they still want to have some responsibility in the care of their spouse. The study hopes to provide details and impactful information of the lives of spouses living separate from their spouse with dementia to benefit other spouses who are in the same situation or one day might be.

Dedication

I dedicate this thesis to the husbands and wives who were apart of this study. Their love and dedication was something so inspiring to me. I cannot begin to imagine the hardships each have to endure through the trials of having a spouse with dementia. Through those interviewing moments it was evident of the love these spouses have for their ill spouse.

Acknowledgments

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Chapter 1: Statement of Research Topic

Introduction

Many married couples have a goal to grow old together, and fulfill the final line of the common vows, “until death do us part” (LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005). Couples who want to stay together until their end years have to keep their bond strong and be prepared to face life’s hardships. One of the most difficult trials and married couple may experience is the illness of their spouse (Wallerstein & Blakeslee, 1996). The researcher conducted the following explanatory study with the purpose to explore marital identity and roles within couples where one spouse has dementia and is living in residential care and the other spouse is living separate in the community. The study was conducted by means of face-to-face interviews with the spouse who was living separate from their spouse with dementia.

Current research has not completely defined the relationship between spouses where one has dementia and is living in residential care, while the other spouse is living out independently in the community. Further research needs to be conducted to greater the understanding of the perceptions of the spouse's marital identity and connectedness, and find out the reasons for consistency in marital identity where it has not been altered by these experiences of having a spouse who has dementia living separate in residential care. The study will contribute to the understanding of how these spouses have role changes within their marriage and how they adapt to the changes.

Statement of the Problem

Growth in Elderly Population

The general population as a whole is living longer than just 40 years ago (World Health Organization, 2014). The longevity of people’s life spans is contributing to the growth of the

elderly population. New advancements in medicine and health are one of main contributors to the longevity of people. The rise in numbers of the elderly population will continue to grow over the years, from the year 2000 to 2010, the number of older people in America increased by 15.3% (U.S Census Bureau, 2011). The average life expectancy globally is about 70 years in 2014, which is 6 years longer than it was in 1990. The average life expectancy is around 80 in the developed countries, which is a dramatic change compared to about 50 years in the developed countries in the early 20th century (World Health Organization, 2014).

Dementia in the Elderly Population

Dementia is becoming a more prevalent disease within elderly populations (Alzheimer's Association, 2014). The growing number of elderly will likely increase the number of people who experience dementia. Dementia is a disease that is caused by damage to the nerve cells in the brain which lead to a shift in one's memory, behavior and ability to think clearly. The most common type of dementia is Alzheimer's and it is estimated that 5.2 million Americans of all ages have Alzheimer's disease in 2014. By the year 2050 it is estimated that nearly sixteen million people will have the disease.

Burden on Caregivers

These changes in behavior and mood can cause many challenges and burdens for the caregiver of that person with dementia (Clyburn & Stones, 2000). Many times the primary caregiver of the person with dementia is their spouse. The illness not only will change the person with dementia, but will bring many challenges and changes within the couple's marriage as often times the roles of relationship shifts (Hayes, Boylstein, & Zimmerman, 2009; Karner& Bobbitt-Zeher, 2005). The burdens from caring for an ill spouse can be too strenuous for the caregiving spouse and ultimately may be unsafe for the spouse who has dementia and the choice may be

made for the spouse with dementia to live in a residential care facility. This transition brings forth different challenges and changes that can happen in the couple's marriage.

Purpose of the Study

The purpose of the study is to determine if and how the spousal identity and spousal roles of the couple have been affected by having to institutionalize the spouse with dementia. The study was conducted to greater the understanding of the perceptions of the spouse's marital identity and connectedness within the marriage, and find out the reasons for consistency in marital identity where it has not been altered by these experiences of having a spouse who has dementia living separate in residential care. The main focus would be upon potential changes in the couples' marital identity as identified by the cognitively sound independent spouse. The census shows that the elderly population is growing which result in a high pressing need for information that involves the elderly. Further research needs to be conducted. The data from this research will contribute to the knowledge and understanding of this topic. Knowledge about the perceptions of role change and adaptation, may be beneficial to social workers who are supporting caregivers. Knowledge that the changes one is experiencing have been experienced by many others may be helpful to reduce the sense of isolation caregivers perceive.

Summary Statement

Through reviewing the literature, it is clear that there is a need for further research of the relationship between spouse where one spouse has dementia and is living in residential care and the other spouse is living independently in the community. People and relationships are complex and there are many things that can be discovered about this specific situation that has not been addressed yet. The vast majority of research has been conducted with a sample of spouses who are still currently living with their spouse who has dementia. There is also much research about

children who now take the caregiving role for their ill parent. Little research attention has been done that focuses on the relationship once they are separated due to having to place their spouse with dementia in residential care, which this study intends to address this gap in knowledge.

Research Questions

1. Has the spousal identity of the couple has been affected by having to institutionalize the spouse?
2. How has the connectedness that the independent spouse feels towards the institutionalized spouse been altered since the separation?
3. Does amount of visitation by the independent spouses reflects their perceptions of their marital identity?
4. What are the reasons for consistency in marital identity where it has not been altered by these experiences?

Chapter 2: Literature Review

Literature Review

Aging Population and the Trends in Aging and Living Longer

The elderly population has been growing steadily through the years, from the year 2000 to 2010, the number of older people in America increased by 15.3% (U.S Census Bureau, 2011). The 2010 census reported that there are approximately 309.3 million people in the United States, nearly 40.4 million were 65 years or older. It is predicted that 20 percent of the population in the United States in 2030 will be 65 years and over (U.S Census Bureau, 2011). Those numbers have noticeably increased from the 13 percent of the population in 2010, and 9.8 percent in 1970. In 2050, the population aged 65 and over is projected to be 83.7 million. The population 85 years and over will double by 2036 and then triple by 2049. A reason for this increased rate of people over 65 is due to the baby boomers. The baby boomers who are surviving in 2050 will be over the age of 85.

There are multiple other reasons why there is a rise in numbers of the elderly population. There have been new advancements in society that have benefited people in general and resulted in longevity of the elderly population. People are living longer today than they were just 40 years ago. One health change that has benefited the population is the decrease of smoking. The decrease of smoking in people 25 to 44 today will lead to a healthier elderly population in 2050 when this age group is 64 to 83 (American Lung Association, 2011). Decrease in smoking is only one contributor to the rise in living longer. There has been an enormous advancement in the medical field in the discovery of curing diseases and rise of vaccinations (Rice and Feldman, 1983). There are new medical advancements being made continually which would mean that the rise in living longer will continue as more problems are solved.

Increased Prevalence of Dementia Particularly Alzheimer Disease

The Alzheimer's Association states that "Dementia is caused by damage to nerve cells in the brain, which are called neurons. As a result of the damage, neurons can no longer function normally and may die. This, in turn, can lead to changes in one's memory, behavior and ability to think clearly. In Alzheimer's disease, the damage to and death of neurons eventually impair one's ability to carry out basic bodily functions such as walking and swallowing. People in the final stages of the disease often require 24 hour care. Alzheimer's disease is ultimately fatal" (2014).

Alzheimer's disease is the most common type of dementia. Alzheimer's disease makes up 60 to 80 percent of all dementia cases. It is reported that one in nine older American's have Alzheimer's disease. An estimated 5.2 million Americans of all ages had Alzheimer's disease in 2014. It is found that 82 percent of those with Alzheimer's disease are age 75 years or older (Hebert, Weuve, Scherr, & Evans, 2010). As the population of elderly people rise, the numbers of people having Alzheimer's disease will also rise. The Alzheimer's Association states that an American is diagnosed with Alzheimer's disease every 68 seconds (2014). The Alzheimer's Association goes on to predict that in 2050, there will be an American diagnosed with the disease every 33 seconds. Nearly sixteen million people will have the disease by 2050. In 2000, there were an estimated 411,000 new cases of Alzheimer's disease. For 2010, that number was estimated to be 454,000; by 2030, it is projected to be 615,000; and by 2050, 959,000 (Hebert, Beckett, Scherr, & Evans, 2001). There is no cure for the disease. Some of the cognitive and behavioral symptoms may be alleviated with the help of medication (Alzheimer's Association, 2014).

There is no treatment today that can slow or stop the progression of the disease, which means the disease is ultimately fatal. Alzheimer's disease is impacting a wide portion of the United States, and with no cure to the disease, it is predicted that the population with Alzheimer's disease will keep growing. The disease not only changes the lives on the elderly person, but it changes the lives of their family and caregivers.

Challenges of Caregiving for Someone with Dementia

The responsibility as a caregiver of someone with dementia can be one of the most trying and mentally exhausting jobs (Clyburn & Stones, 2000). There are many burdens and struggles that come with caring for a person with dementia. Many times the daily changes that come along with caring for someone with dementia can be a great struggle within itself (Sherwood, Given C., Given B., & Von Eye, 2005). The family caregivers have to adjust to the changes of their family member's losses in judgment, orientation, and the ability to communicate effectively (Alzheimer's Association, 2014). As the mental state of the person with Alzheimer's disease change, so does their physical state, and there is a high need for supervision and aide with personal care.

Fifty-nine percent of family caregivers of people with Alzheimer's and other dementias rated the emotional stress of caregiving as high or very high (Alzheimer's Association, 2014). The Sherwood study found that the burden of caregiving for someone with dementia can be linked to depressive symptoms (2005). Caregivers often have to face disturbing behaviors from their loved ones that can be hard to handle (Clyburn & Stones, 2000). Another burden is that the patient's functionality is limited, and the extra dependency that the patient has for the caregiver can cause a greater amount of stress. Along with stress and depressive symptoms, another burden that affects someone who is caring for an ill family member is a financial burden. Many family

caregivers reduce their work hours to care for their ill family member (Covinsky, Eng, Lui, Sands, Sehgal, Walter, et al., 2001). Sometimes caregivers lack the support from family which would likely increase the burden of caring for someone with dementia. Frequently the primary caregiver to a person with Alzheimer's disease is their spouse.

Marital Roles, and the Impact of Spouse's Illness upon Roles

After a few years of marriage many couples develop certain roles within their marriage. These types of roles can differ widely as can which spouse adopts those roles. These roles may include household task, child rearing, finances, making large family decisions, etc. Over the years as the couple ages, these roles are likely to change. A prominent reason for the change would be due to poor health of one of the spouses. As Alzheimer's disease progresses, the spousal identities and roles are likely transformed (Hayes, Boylstein, & Zimmerman, 2009; Karner & Bobbitt-Zeher, 2005). The responsibilities and roles within the marriage may shift to a more independent or separate identity due to one of the spouses having to take on more since their spouse has dementia (Kaplan, 2001).

The primary shift of roles is for the spouse who is now caring for their loved one with dementia. Some may believe that the role of being a spouse is incompatible with the role of caregiving. Their roles have now shifted to that of caregiver, nurse, friend, or guardian and they no longer take on the role as spouse (Adams, Wampler, & Kaszniak, 2001). One study found that spouses do not lose their role as husband or wife when caring for their spouse with dementia, but take on an equal role as primary spouse or spouse caregiver (Baikie, 2002).

The shift in roles can affect people differently. The relationship that the couple had established in their marriage influenced the way spouses react to the change of now caring for a spouse with dementia. In one study it was found that the male caregiver was comfortable with

his new role of caring for his wife and taking on the extra responsibilities, because early on in the marriage he had established the role of provider. However, another male caregiver began feeling bitter because of all the work in the house fell on his shoulders. In their marriage before his wife was ill she would have assumed more of the duties associated with maintaining the home (Harris, Adams, Zubatsky, & White, 2011). The caregiving roles and marital roles can shift once more when the spouse cannot longer meet the needs of their ill spouse and place their spouse in a care facility.

Impact on Marital Roles when One's Partner in Residential Care

Another study question is the impact of separating spouses when the spouses are separated due to having to institutionalize the spouse with dementia into a care facility. Care facilities are an option for a spouse who can no longer care for their spouse who has dementia. In the United States there are 15,700 nursing homes, and the total number of residents of those homes are approximately 1.5 million (Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013). Some care facilities provide extensive care for those who have dementia. Of 1,000 people in a skilled nursing facility 349 are those with Alzheimer's disease or other dementias.

When a spouse decides to admit their spouse into a long-term care facility that can change the way the spouse interacts in the marriage. Studies have found that placing a loved one in residential care can cause a depressive outcome in the person making the decision. (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Gaugler, Pot, & Zarit, 2007; Schulz et al., 2004). Grief and sense of loss is the strongest for a spouse caregiver who is placing their spouse in a nursing facility (Meuser & Marwitt, 2001).

The grief and loss from placing a loved one in a nursing home can have an effect on the marital relationship of the couple. The giving up the role as their spouse and becoming a full-

time caregiver is one of the most difficult decisions for a spouse, which leads to stress (Nay, 1996). There is a greater sense of loneliness and isolation for the spouse who is living in the community (Chene, 2006). Many issues with the shift in roles can cause, “resentment, guilt, distancing, and erosion of intimacy” (Rolland, 1994, p. 331). Studies have found that the marital relationship of an elderly couple can be greatly affected by the placement of one spouse in a care facility, and much of the negative outcomes of the placement can be linked to previous marital conflict within the marriage (Vassallo, 1995).

The census predicts the rise in the elderly population. As the elderly population rise, so do the number of people with diseases that in that population, mainly Alzheimer’s disease and other dementias. Alzheimer’s disease affects many people in the elderly population. There are many changes that come with Alzheimer’s disease and many of the burdens are placed on the caregivers. Often the caregiver of someone with Alzheimer’s disease is their spouse. When the duties of caring for their spouse are too much, the spouse has to consider the option of placing their loved one in residential care. The move to a care facility can cause a shift in marital roles and the relationship between the spouses. The information gained from the study may potentially benefit other spouses who are in the same situation as the participants in the study. The study may ask provide insight to social workers who specialize in geriatrics to better understand the relationships between spouses where one spouse has dementia.

Chapter 3: Methodology

Research Design

To understand the spousal connectedness of a married couple where one spouse has dementia and is institutionalized in a care facility and the other spouse lives independently in the community the researcher will implement a descriptive qualitative study. The resultant data analysis will determine the presence of themes identified from the interviews. The design is set up to be an interview to explore the marital relationships. The interview will consist of open-ended questions that will concentrate on the spousal identity of the spouse whose partner has dementia and is institutionalized in a care facility. The interview will answer the main objectives:

1. Has the spousal identity of the couple has been affected by having to institutionalize the spouse?
2. How has the connectedness that the independent spouse feels towards the institutionalized spouse been altered since the separation?
3. Does amount of visitation by the independent spouses reflects their perceptions of their marital identity?
4. What are the reasons for consistency in marital identity where it has not been altered by these experiences?

The questions were answered by face-to-face interviews conducted by the researcher with the spouse who is living independently from their spouse with dementia.

Sampling Procedure

Spouses of someone with dementia were recruited using convenience sampling. The researcher recruited men and women who live in central Ohio whose spouse is living in a care

facility and is diagnosed with dementia. Nine participants were recruited. Interview respondents volunteered to participate in the survey and were not randomly selected. The findings are based solely on the responses and are not generalizable to the entire population of spouses who have a spouse living in residential care with dementia.

The target sample for this study was set for 10 participants. This number was chosen because it is a reasonable number to manage the data in the time period, but allows diversity throughout the participants.

Data Collection Procedures

The data collection process began after approval of the study from The Ohio State University's Institutional Review Board. All data was collected by means of face-to-face interviews. All participation was voluntary, although there was an incentive to encourage involvement. Each participant received a \$20 dollar gift card presented to them at the beginning of the interview. The interview consisted of five open-ended questions aimed at the main objectives, with sub-questions to bring further clarity to the root question as needed. The interviews individually lasted about 45-60 minutes, and participants could end the interview at any time if they were uncomfortable or for any other reason. The participants would still receive their gift card even if the interview was not completed.

Interviews took place in a private location mutually agreed upon by the student and the participant. There was no need to know the identity of the participant due to the research study just being done at one point. Participants will not be asked their names. The interviews were recorded and then later transcribed to allow for data analysis. The data that has been collected in the study will be destroyed after five years.

The data were collected by the BSW honors researcher in order to fulfill the requirements of an undergraduate thesis. The researcher recruited participants for the interviews by advertisement flyers (appendix B). The flyer described the purpose of the study, the approximate length, and indicated that participation was voluntary. The flyers were posted on facility information boards that were visible to visitors to the facility. If someone was interested in participating in the study they were instructed by the flyer to contact the researcher by phone or E-mail. The researcher then distributed the flyers to the approved residential care facilities.

Measures

The interview questions were created to determine the factors related to the purpose of the study. These factors included marital roles and identity, spousal connectedness, marital satisfactions, and visitation. The specific questions were designed with the main objectives in mind. The questions consisted of open and close ended questions that would help the research gain insight on the objectives. The questions were designed to not overlap and ask the same question twice. A pilot study was done to judge the effectiveness of the questions. The design of the questions was informed by a review of the literature.

Data Analysis

Coding the data involves breaking down the large data which was collected into smaller categories. The analysis focused on the identification of themes, i.e., underlying ideas, assumptions, and conceptualizations, through a coding process that will progress from description to interpretation. The analysis focused on identifying similarities as well as differences within and across the individual spouses.

The researcher analyzed the data in accordance with recommended coding methods, including at least three coding strategies: open and selective coding of the data, and memoing. The process of analysis the data included breaking down the text to discover relations, similarities, and dissimilarities within the data. Coding the data involved developing concepts from the data and then categorizing those concepts. (Berg, Lune, & Lune, 2004). Selective coding comes from the open coding to select a core category to base all the other categories to (Strauss, & Corbin,1990). The core category of this study was marital identity.

After the interviews were transcribed, the researcher began open coding, scrutinizing the transcripts line-by-line and identifying emerging themes. The researcher then inductively and deductively compared and contrast categories. During the coding process the researcher wrote memos about their decisions, thoughts, and interpretations.

Chapter 4: Results

Demographics of the Sample

The sample size of the study included nine participants. There were six women and three men in the sample. The longest length of marriage was 66 years and the shortest length of marriage was 31 years. The average length of marriage was 56 years. All the participants lived no more than 20 minutes from their spouse.

Summary Analysis

The analysis of the data found that. There were four themes that emerged from the study which related back to the main objectives. The themes found were:

1. The spouses have accepted their roles as husband or wife as they are no longer the primary caregiver, but they still want to take that responsibility to make sure their spouse is taken care of.
2. The spouses are dedicated to visiting their ill spouse due to their love for them, and not just out of obligation.
3. The spouses are satisfied with their marriage at this point in their life, and reflect upon good memories from the couple's past to cope with the struggles they are facing currently.
4. Spending time with their spouse is what keeps them bonded in this stage of the marriage.

Roles within the Marriage

It was unanimous from the interviews that the roles in the marriage changed tremendously as the spouse's illness progressed. The healthy spouse began to take on tasks and roles little by little, before they soon were doing most things. The spouses all said that the change of role was gradual. Most of the women expressed that they now see themselves almost like a

mother to their husband and that they are the ones leading the marriage. All spouses reported that their primary role is to see that their spouse is getting the care they need. Many expressed their decision to place their spouse in the care facility. They said that even though it was very hard they knew that it was something that had to be done. They were not capable of giving the care to their spouse as they needed.

“In some ways it is actually better that we are apart because she is getting her maximum care and I am not getting worn out. I didn’t feel good making the decisions to put her in the memory care, but I knew had to do it. One of the unfair things about life is an old person trying to take care of an old person. It just doesn’t work. For one thing we don’t have the energy.”

Visitation of Spouse

All of the spouses would visit their spouse at least three times a week, and the majority of them would visit their spouse every day. The interviews showed that there were two types of visits. The first was when the spouse being visited at the memory care unit was very responsive to the visit of their spouse. “He looks forward to seeing me and is so glad when I am there.” The spouses who had these kind of visits stated that the visits were very meaningful for both them and their spouse. The second type of visit was when the spouse being visited at the memory unit was unable to speak or did not know their spouse. This caused the visit to be very one sided. In these cases, the spouse visiting felt that the visits were not as meaningful, but they still seemed to be helpful for the spouse visiting. All spouses agreed that they are motivated to visit their spouse out the love they have for their spouse and not just out of obligation. One spouse states, “When you have a spouse that long and you both know that you have been true for the whole time, that is your life, it is your other half, and it is part of you.”

Satisfaction of Marriage

Many spouse reported that they are still satisfied with their marriage and if anything, this situation has made them value their relationship more. From speaking with the spouses it is clear that all the spouses were satisfied with their marriage, and although this is not the situations they hoped for, they are able to reflect back on the good memories of their marriage. The reflection of their marriage provides a coping mechanism to deal with the struggles and burdens the spouses may face when living separate from their spouse with dementia. One respondent stated:

“I am very satisfied. At times I get discouraged or blue and sometimes I think, ‘Is this all there is?’ No there isn’t this is a month out of 57 year, when I’m tempted to go there I have to think yes, but look at our family, look at the jobs we’ve had, look at the traveling we’ve had. Nobody would vote for this, I wouldn’t wish this on anyone, but here it is. “

Bond with Spouse

The spouses whose husband or wife who were still able to recognize them all stated that their bond with their spouse was stronger than ever and most spouses are still able to connect with their spouse,

“Every marriage has its own language, its little jokes, is little litanies, its phrases, and songs. Those are still there. I can still play off those and make him laugh and he’ll have a turn of phrase that will just crack me up. If our bonds are ropes anymore at least they are a lot of threads that still hold us.”

The spouses whose husband or wife did not know who they were stated that their bond was not as strong because most interactions were one sided and it is hard to feel connect to someone who did know who they were. The theme that was found for what keeps their bond

strong in the marriage was just from the times they spouses were able to spend time together.

The majority of the spouses cannot do the things with their spouse that once kept their bond strong like, going to plays or traveling, but they are still able to be together, which ultimately is the thing that keeps their bond strong. Their bond was not determined by the things they did, but by the time they were able to spend together. One spouse stated, “Our relationship and being together is what keep us connected.”

Chapter 5: Discussion

Summary of the Results

Spousal Identity and Consistency

The study was designed to determine if the spousal identity of the couple has been affected by having to institutionalize the spouse. A second goal was to listen for explanations of both changes and consistency in marital identity where it has not been altered by these experiences.

Even with the gradual changes in the spouse's marriage, the spouses all identified as either husband or wife. They have accepted the changes in their marriage and the new roles that they have. Now that their spouse is in residential care, they are no longer the primary caregiver, but they all want to take that responsibility to make sure their spouse is getting the care they need.

Much of the consistency in their marriage satisfaction emanates from their ability of the spouses to look back on all the good memories that they had in their marriage. The good memories in their marriage and being able to reflect on those is what brings the spouses strength and helps them cope with the changes and struggles of having a spouse with dementia.

Connectedness of Spouses

Another purpose of the study was to examine how the connectedness that the independent spouse feels towards the institutionalized spouse has been altered since the separation. There is no doubt the connection between the spouses have changed due to the separation. One of the spouses stated that, “an empty bed, is an empty feeling.” Even though there are some changes within the marriage connection, the findings showed that the spouses still felt connect to their

spouse. The main thing that keeps the bond and connection constant within the marriages is the desire for the spouse to be with their spouse. The time they share together is all they need to stay connected. Although these times are very different from previous times spent together many years ago, they still mean something special in the marriage.

Visitation

The final aim of the study was to discover if the amount of visitation by the independent spouses reflects their perceptions of their marital identity. The visitation of the spouses did fluctuate from visiting every day to visiting around three times a week. All spouses were motivated to visit their spouse due to the fact that they loved them and were dedicated to being their spouse. They did not just visit their ill spouse due to obligation. The spouses want to visits to see their spouse and make sure they were getting the proper care.

Limitations

Limitations of the study included that unavoidably the participants answers to the interview questions could have been affect by having the researcher present. Additionally, the study was limited by the smaller sample size. The study participants only consisted of individuals who did visit their spouse. There was no diversity of the data from spouses who does not visit their ill spouse. An earlier start in data collection would have increased the time needed to interview more participants.

Implications and Future Research Recommendations

The study findings will hopefully be a beneficial contribution to the literature on spousal caregiving for their spouses with dementia. The specific study hoped to benefit spouses who are in similar situations as the spouses who were interviewed. Practice implications of the study are

making sure that facilities are sensitive to the spouses by providing them with a good space to visit and encouraging activities for them to do together. Also that there are support for helping spouses cope with grieving and coming to terms with the functional changes. This could be something like a support group or informational workshops for caregivers.

While the information found from this study is beneficial and contributes to the research of spouses of someone with dementia, there are many more aspects of the relationship between a caregiver and someone with dementia that can be further explored. For future research, the study could explore deeper into the coping mechanism that the spouses have and what things were most beneficial to them during the transition of placing their loved one in a care facility. The literature review explained that having a spouse with dementia can cause many struggles and burdens. It would be beneficial not only to the spouse to research more about coping skills, but it would also benefit the spouse with dementia because the independent spouse would respond to the struggles and burdens in a healthy manor and not project their negative feelings toward their spouse.

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Appendix A: Recruitment Script

Recruitment Script (to be read if responded makes inquiry by phone or emailed if contact occurs that way):

Subject Line: Opportunity to Participate in Student Research Study

Hello my name is Rachel Hornsby. I am a student at The Ohio State University, and I am studying Social Work. I am in the honors program, and I am conducting a research project as a portion of that program. I am hoping to learn more about the experience of persons like yourself who has a spouse who now resides in a dementia care facility. More specifically, I want to learn about how you may have experienced changes in the roles each of you play as partners, and how you see each of your roles now. My study has been approved the Ohio State University Institutional Review board and is being supervised by a faculty member at Ohio State, Tom Gregoire. If you choose to participate I will interview you for a total of about 45 minutes. I will record your interview, but will not retain any information that identifies you. For your trouble, I will provide you a gift card for Target. Are you interested in participating in this study? If so I have a consent for you to sign that contains more information.

Appendix B: Recruitment Flyer

Would you be interested in participating in a student research project?

This study is designed to assess the relationship between spouses where one spouse has dementia and is living in a care facility and the other spouse is living independently in the community. If you are over 50 and have a spouse living in the Memory Care Unit you are eligible to participate.

- The study consist of one interview with a student researcher lasting up to 45 minutes
- The interview will explore your current relationship to your spouse.

Participants will receive a \$20 gift card!

The findings of the study may help others who have a similar situation of having a spouse living separate in care facility.

If you would like to hear more about the study or are interested in participating, please call or e-mail Rachel Hornsby at (740) 244-9186 or hornsby.16@osu.edu

Appendix C: Informed Consent Form

The Ohio State University Consent to Participate in Research

Study Title:	Perceptions of Marital Identity of a Spouse Living Separate from their Spouse with Dementia
Researcher:	Tom Gregoire, a faculty member at the Ohio State University is the Principal Investigator for this study. Rachel Hornsby, an Ohio State University student is also working on this study.
Study Purpose:	The purpose of this study is to learn, through individual interviews, about the experiences of caregivers who have a spouse with dementia. The study is part of an undergraduate honors thesis and seeks to learn how marital roles may have changed as a result of dementia and the needs to place one's spouse in residential care.
Study Procedure	<hr/> <p>The study consists of an individual interview with Rachel Hornsby. The interview will take place in a private location and consist of about five questions regarding your experience with how spousal roles may have changed with the onset of your spouses dementia and his or her move to a residential care facility.</p> <p>There is one interview and it should last about 45 minutes. You are not required to participate and may end the interview at any time. Your decision to participate or not will have no impact upon services you or your spouse receive from the care facility. Staff at the facility will not be made aware of your decision to participate or not participate.</p>

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

Your participation is voluntary.

Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate. If you decide to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose: To determine if the spousal identity of the couple has been affected once a spouse with dementia moves into a residential care facility.

Procedures/Tasks:

If you take part in this study, you will be asked to:

- Complete one interview conducted by the student which is estimated to last 45-60 minutes
- The interview, with your permission, will be audio recorded.

Duration: One time interview, estimated to last 45-60 minutes

You may stop participating in the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with persons and organization that provide care to your spouse.

Risks and Benefits:

We are unsure if you will receive any benefits by taking part in this research study. The study will provide you and opportunity to tell your story and perhaps gain new perspectives about your relationship as it has changed since the onset of your spouse's dementia and placement in residential care.

This research is considered to be of minimal risk. That means that the risks associated with this study are the same as what you might face every day. There are no known additional risks to those who take part in this study.

Confidentiality:

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;

Incentives:

Participants will be provided with \$20.00 gift certificates to Target at the beginning of the interview.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. You will retain the gift card even if you stop the interview before answering all of the questions. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study, or if you feel you have been harmed as a result of study participation, you may contact Thomas Gregoire at 614-292-9426, or Gregoire.5@osu.edu

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

<hr/>	
Printed name of subject	Signature of subject
<hr/>	
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AM/PM	
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Date and time	
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Printed name of person authorized to consent for subject (when applicable)	Signature of person authorized to consent for subject (when applicable)
<hr/>	

	AM/PM
Relationship to the subject	Date and time

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining consent	Signature of person obtaining consent
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	AM/PM
	Date and time

Appendix D: Interview Question Guide

Opening question:

- Can you describe a typical visit with your spouse?

(1) to determine if the spousal identity of the couple has been affected by having to institutionalize the spouse

- Please tell me about your marital roles, such as cooking, finances, housework etc and how they have changed with the recent changes in your marriage.
- How long have you been married, and how long ago did your spouse enter a care facility?
- What was your connection like in your marriage prior to your spouse's illness? How has it changed, and what is it like now?
- How have the recent changes impacted your level of satisfaction with your marriage?

(2) to examine how the connectedness that the independent spouse feels towards the institutionalized spouse has been altered since the separation

- Please tell me about your marriage now that your spouse is in the care facility
- How do you see your marital role now?
- How do you feel about your marital role?
- How satisfied are you with your marriage at this stage of life?

(3) to discover if the amount of visitation by the independent spouses reflects their perceptions of their marital identity

- Please tell me about the times you visit your partner
- How often do you visit?
- How meaningful are the visits to you?
- How do your visits help with the current situation?
- What motivate you to visit your spouse?

(4) to find out the reasons for consistency in marital identity where it has not been altered by these experiences.

- How strong is your bond today?
- Please tell me the things that keep your bond strong
- What do you do when you're having a rough day with your spouse?
- How do you keep the bond there?
- Explain your support system
- What are things you and your spouse did that kept you connected before he/she moved?
- Do you still do those things now that you are living separate?